

An interpretive investigation of perinatal HIV
transmission:
From the population to the personal

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A thesis submitted in fulfilment of the requirements of
Doctor of Philosophy

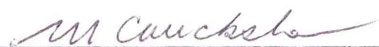
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I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Student

A handwritten signature in cursive script, appearing to read 'M. Canckale', is written above a horizontal line.

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Abstract

While there have been many studies investigating perinatal HIV infection, few have addressed the complexity of the disease. The complexities of HIV infection are compounded for families affected by the disease where several family members are infected. HIV infection is a particularly challenging disease when it affects children and their families as it has the potential to extinguish whole families, placing an infected family under extreme stress. The multigenerational impact of the disease, where several family members are infected and where multiple losses may have occurred as a result, severely affects the family's ability to cope with existing problems.

This dissertation explores the experience of children with perinatal HIV and their carers using an interpretative methodology to synthesise understandings from three separate epidemiological, case study, and interview studies. A review of data from the National Perinatal HIV Register provides information on perinatal transmission of HIV in Australia; a case study demonstrates the medical complexity of the disease from diagnosis to treatment while interviews with parents and children provide insight into the effects of the disease. The study is predicated not only on the research undertaken for this study but also on clinical experience of the researcher.

The findings demonstrated that although HIV is a relatively rare disease in Australia transmission continues despite strategies which have demonstrated efficacy in preventing transmission from mother to child. Perinatal transmission continues to occur especially when women give birth before a diagnosis is made. The experiences of parents caring for children with HIV infection, although varied, demonstrate the complex nature of HIV. Once diagnosed with HIV, parents find themselves undertaking a fine balancing act during which they must negotiate to strike the right equilibrium for their family to endure the circumstances as best they can. They are faced with contradictory decisions in which, for example, they must disclose their HIV status to others to receive the support necessary to survive the emotional turmoil created by the disease.

Children's experiences of living with perinatal HIV infection are an ongoing process. Most of the children who were interviewed for this study had been affected by HIV either through severe ill health or by the death of one or both parents. Thus, for all the children, HIV was a very real entity even though at the present time all were now well and attending school full time.

Across all major themes is the cumulative effect of HIV disease on the child and family. It is the cumulative effects of HIV that presents the greatest challenge for families and clinicians and it is this challenge that underpins the study.

This study represents the beginning of a systematic approach to an examination of how and why Australian children have been infected through mother to child transmission and explores the perceptions and experiences of children and their families. It is hoped that this research will provide health care providers, managers and researchers an understanding with which to guide the care of children and their families living with perinatal HIV.

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